



Finding a patient support group

Christopher Newell, Associate Professor of Medical Ethics, University of Tasmania, Hobart

Summary

There are many advantages in referring patients to self-help groups as part of medical care. These groups can be face-to-face and on-line. Some of the questions patients should ask when choosing a patient support organisation include whether there is provision of social and emotional support, what helping mechanisms are offered, and whether it is a disease- or treatment-specific group. It is useful to enquire about the experiences and perceptions of others and the appropriateness of the information provided about the disease or disability. Questions should be asked about fees and charges, sources of funding and whether the organisation is democratically accountable.

Key words: consumers, information services.

(*Aust Prescr* 2004;27:19–21)

Introduction

'For the first time in my life I felt that I was talking with someone in a secret language that only the two of us understood ... I had never before met anyone with the same condition. The impact was immense. Here there was someone who could understand and he was not a doctor or a psychologist, and he did not look down upon me from above, or suspiciously at me from the side. He didn't ask me questions to diagnose me and he shared with me openly what he was feeling. Something different, new, right, refreshing. Something that released me from the constant need to keep that terrible secret hidden inside.'¹

It is in this way that Shula Alperovitch, a mental health consumer, introduces her first tentative steps of encountering and fostering peer support via a self-help organisation. Various manifestations as patient support organisations, consumer organisations or self-help groups, these organisations are supported by a strong body of literature which points to their importance. Indeed, it shows that they not only provide peer support but can optimise health outcomes.²

There are two types of organisations. First, there are the face-to-face organisations that often operate around particular illnesses. Secondly, there are an increasing number of on-line self-help

groups. These can be of particular assistance to people with rarer conditions, and for people who want to find information on sensitive issues or private concerns that they may not otherwise be prepared to raise with a health professional.³

Health professionals may be asked to recommend a self-help group. While the patients will decide which group suits them best, health professionals can provide advice on what questions to ask.

Face-to-face peer support

Many self-help and patient support groups in Australia form at the local level and gradually expand to operate as organisations at the State or Territory level. Some of these organisations have federated at the national level to maximise their lobbying, support and political power. Organisations with a presence across Australia are routinely mentioned in *Australian Prescriber*. However, there are many patient support organisations which may be of significant assistance but they are not present in all States and Territories. In some States these organisations may be easier to locate if they are members of, or affiliated with, umbrella consumer organisations. Some self-help groups may also be associated with charitable foundations.

There are variations in consumer-controlled self-help groups. They include:

- consumer advocacy groups (where the benefit comes from the outward focus on changing health service delivery and the peer interaction is incidental but still immensely supportive)
- support groups facilitated by non-government organisations (which utilise semi-professional facilitators but rely on peer interaction for their effectiveness).

Some groups are now forming national alliances of related conditions or are forming as national groups for rare conditions (e.g. brain tumours) facilitated by increased access to low cost communications via the internet or teleconferencing.

Making contact

There is no easy way of locating patient support organisations, although a search through the phone book and increasingly the world wide web will often yield results. Even small community organisations these days are increasingly supported by State government programs to provide at least a presence on the internet. Sponsorship of organisations or web sites may also be offered by corporate sponsors such as pharmaceutical companies.

There are individual state directories of self-help groups in electronic and paper formats, but the paper copies quickly become out of date. Some organisations are listed in the Therapeutic Guidelines books and the Australian Prescription Products Guide, while MIMS attaches a listing to the CD-ROM version of its drug guide. Links to some organisations are also to be found on the Commonwealth Government's Health *Insite* (www.healthinsite.gov.au). Local councils are a good source of information and often have local directories.

Sadly for rural consumers, many of the state organisations tend to be centred on the capital city. However, contacting the secretariats can still be extremely useful because many organisations have isolated members in rural areas. There is also the organisation Health Consumers of Rural and Remote Australia which can provide guidance (www.ruralhealth.org.au/hcrra/index.html).

Examples of other useful contacts include the Health Consumers' Council of Western Australia (www.hcc-wa.global.net.au), and organisations such as the Collective of Self-Help Groups (<http://home.vicnet.net.au/~coshg/>) and the Chronic Illness Alliance of Victoria (www.chronicillness.org.au). More specialised contacts include such organisations as Cancer Voices NSW (www.cancervoices.org.au). In Australia a wide variety of self-help organisations with appropriate constitutions geared towards consumer self-help are also members of Consumers' Health Forum of Australia (www.chf.org.au).

On-line self-help groups

Increasingly there is significant activity and development by healthcare consumers on the world wide web.⁴ This movement is particularly important with regard to people who have comparatively rare conditions or want the anonymity of the internet.

'On-line groups – self-help and mutual aid groups – found on internet news groups, commercial information networks, and computer bulletin boards are potential resources ... because they combine the advantages of self-help and the accessibility of computer networks.'⁵

These on-line groups are important for people who live with chronicity and disability. Searching for these groups can be as simple as using a search engine to trawl the web. However, the questions listed below will be of vital importance in evaluating how useful such on-line contacts are. In addition, it is important to note that while particular protections exist under Australian law with regard to membership of organisations, consumers need to be aware of the fact that Australian laws and conventions (such as consumer protection and privacy) are not necessarily to be found in the global on-line community.

Some questions: making an informed choice

Health professionals may not be aware of the relevant support group for a particular patient, or they may forget to suggest that

the patient considers joining a group. In such circumstances, exploring the appropriateness of a choice made independently of a professional can have a vital role in the therapeutic relationship. It is not just a matter of finding an organisation, but also enabling patients and their families to work out whether or not this is the appropriate organisation for them. They should establish whether bias may be introduced into the information given by a sponsor such as a drug company or healthcare provider. It is particularly important that any financial ties or sponsorships which may influence their stance on particular matters such as treatments are known when choosing or evaluating a support group.

Does the organisation provide social and emotional support?

The organisation and its members may provide support or empathy, social support, and the opportunity to explore the fact that 'I am not alone', to express feelings or catharsis, express and develop friendship, and explore 'taboo topics' such as sexuality. Provision of information on the illness and its treatment, for example to dispel mystery or uncertainty, can itself be very emotionally supportive.

What are the origins of the organisation?

For example, it is important to know if a group has been formed by people opposed to a particular treatment, or by researchers trying to recruit a cohort of patients for study.

Is the information about disease/disability reputable and appropriate?

Checking whether or not the organisation is drawing upon reputable healthcare information is vital. Where consumer information is used, such as in qualitative research, about the experience of consumers with a particular condition, has a methodology been used which is open to scrutiny?

Is the organisation democratically accountable?

Checking that the organisation has a constitution which allows participation by members and ensures their rights, including the ability to participate in governance, can be important.

Is there information about funding sources and potential conflict of interest?

The organisation in its publicly available literature (such as an annual report) should make clear where it gets its funding from (including funding for projects). Ask carefully if there are any contractual arrangements with pharmaceutical companies or other healthcare providers, as these arrangements may significantly influence the information provided. The problems include possible bias, and even the possibility of recruitment to a particular trial or treatment to the exclusion of others. Indeed organisations that accept such sponsorship may face constraints in critiquing a particular service or drug.

Does the organisation offer helping mechanisms?

For example, does the organisation provide avenues for problem solving and an exchange of ideas where people can offer specific advice or ask questions? Indeed, does it provide an environment of support where no question about a condition is the 'wrong' question?

Is the organisation disease- or treatment-specific?

While some organisations have developed around particular treatments there is much to be said for suggesting that people take a broader approach to self-help. Organisations revolving around a particular treatment can unnecessarily limit options and information options about other treatments and support.

What are the perceptions of others?

Find out what other people including health professionals (other than members of the management of an organisation) think about that organisation and the contribution it can make. Consumers should be encouraged to talk to a health professional if they think the support organisation is providing misleading or questionable information.

What are the fees and charges?

Informed financial consent is vital. People need to know what they actually get for any membership fees and whether this represents value for money for them. It is important to realise that free or subsidised membership may well reflect corporate sponsorship which may be relevant when considering membership.

Conclusion

Patient support organisations provide significant support which can complement contemporary medical care. There are many advantages in referring patients to self-help groups, but they should ask questions before joining the group. Ask the patients how effective and helpful such organisations are, because many community organisations change over time. Their experience can then inform other patients seeking support.

E-mail: Christopher.Newell@utas.edu.au

Acknowledgement

I acknowledge with gratitude the assistance of Ms H. Hopkins and Mr R. McGowan in researching this article.

References

1. Alperovitch S. The consumer movement in mental health care. *Isr J Psychiatry Relat Sci* 2002;39:159-64.
2. Trojan A. Benefits of self-help groups: a survey of 232 members from 65 disease-related groups. *Soc Sci Med* 1989;29:225-32.
3. Hopkins H, Fogg S. Assessing health information on the Internet. *Aust Health Consum* 2002;2:21-3.
4. Milio N. Engines of empowerment: using information technology to create healthy communities and challenge public policy. Chicago: Health Administration Press; 1996.
5. Finn J. An exploration of helping processes in an online self-help group focusing on issues of disability. *Health Soc Work* 1999;24:220-31.

Associate Professor C.J. Newell, AM, is a member of the governing committee of Consumers' Health Forum.

Your questions to the PBAC

Australian Prescriber readers are invited to write in with their questions about decisions of the Pharmaceutical Benefits Advisory Committee. The segment 'Your questions to the PBAC' will publish selected questions from readers, and answers from the Committee itself. Questions may address issues such as regulatory decisions, pharmaceutical benefits listings, withdrawal of a drug from the market and Authority prescriptions.

This exclusive arrangement helps *Australian Prescriber* readers understand how the contents of the Schedule of Pharmaceutical Benefits are determined. The 'yellow book' is published quarterly by the Department of Health and Ageing,

and is also available on the internet at www1.health.gov.au/pbs/index.htm. It provides important information for doctors, dentists and pharmacists including a summary of changes to listed items, which medicines are included or excluded from benefit, whether restrictions apply to medicines and how much patients should pay including price premiums for particular brands where applicable.

It may not be possible to reply to all individual questions. The usual editorial controls will apply so that readers' letters and the responses selected by the Editorial Executive Committee will be published in the journal. Letters and responses may be edited before publication.